

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Single Technology Appraisal

### Fenfluramine hydrochloride for treating Lennox-Gastaut seizures in people aged 2 and over ID1651

#### Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>• UCB (fenfluramine hydrochloride)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• Brain and Spine Foundation</li> <li>• Brain Charity</li> <li>• Contact</li> <li>• Dravet Syndrome UK</li> <li>• Epilepsy Action</li> <li>• Epilepsy Society</li> <li>• Neurological Alliance</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> <li>• SUDEP Action</li> <li>• Young Epilepsy</li> </ul> <p><u>Professional groups</u></p> <ul style="list-style-type: none"> <li>• Association of British Neurologists</li> <li>• British Geriatrics Society</li> <li>• British Neuropathological Society</li> <li>• British Paediatric Epilepsy Group</li> <li>• British Paediatric Neurology Association</li> <li>• Epilepsy Nurses Association</li> <li>• Institute of Neurology</li> <li>• International League Against Epilepsy UK</li> <li>• National Neuroscience Advisory Group</li> <li>• Neonatal and Paediatric Pharmacists Group</li> <li>• Neuromodulation Society of UK and Ireland</li> </ul>	<p><u>General</u></p> <ul style="list-style-type: none"> <li>• All Wales Therapeutics and Toxicology Centre</li> <li>• Allied Health Professionals Federation</li> <li>• Board of Community Health Councils in Wales</li> <li>• British National Formulary</li> <li>• Care Quality Commission</li> <li>• Department of Health, Social Services and Public Safety for Northern Ireland</li> <li>• Epilepsy Wales</li> <li>• Healthcare Improvement Scotland</li> <li>• Medicines and Healthcare Products Regulatory Agency</li> <li>• National Association of Primary Care</li> <li>• National Pharmacy Association</li> <li>• Neurological Alliance of Scotland</li> <li>• NHS Confederation</li> <li>• Scottish Medicines Consortium</li> <li>• Wales Neurological Alliance</li> <li>• Welsh Government</li> <li>• Welsh Health Specialised Services Committee</li> </ul> <p><u>Possible Comparator Companies</u></p> <ul style="list-style-type: none"> <li>• Accord Healthcare (clobazam, lamotrigine, topiramate)</li> <li>• Aspire Pharma (sodium valproate)</li> <li>• Atnahs Pharma (clobazam)</li> <li>• Aurobindo Pharma (lamotrigine, topiramate)</li> <li>• Desitin Pharma (sodium valproate)</li> <li>• Eisai (rufinamide)</li> <li>• Gerot Lannach UK (sodium valproate)</li> </ul>

Provisional stakeholder list for the evaluation of fenfluramine hydrochloride for treating Lennox-Gastaut seizures in people aged 2 and over ID1651

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<ul style="list-style-type: none"> <li>• Primary Care and Community Neurology Society</li> <li>• Royal College of General Practitioners</li> <li>• Royal College of Nursing</li> <li>• Royal College of Paediatrics and Child Health</li> <li>• Royal College of Pathologists</li> <li>• Royal College of Physicians</li> <li>• Royal Pharmaceutical Society</li> <li>• Royal Society of Medicine</li> <li>• UK Clinical Pharmacy Association</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Department of Health and Social Care</li> <li>• NHS England</li> </ul>	<ul style="list-style-type: none"> <li>• GlaxoSmithKline (lamotrigine)</li> <li>• Glenmark Pharmaceuticals Europe (topiramate)</li> <li>• GW Pharma (cannabidiol)</li> <li>• Janssen-Cilag (topiramate)</li> <li>• Martindale Pharma (clobazam)</li> <li>• Mylan (lamotrigine, topiramate)</li> <li>• Rosemont Pharmaceuticals (clobazam, topiramate)</li> <li>• Sanofi (clobazam, sodium valproate)</li> <li>• Seacross Pharmaceuticals Ltd (sodium valproate)</li> <li>• Somex Pharma (sodium valproate)</li> <li>• Thame Laboratories (clobazam)</li> <li>• Viatris (felbamate)</li> <li>• Wockhardt (clobazam, sodium valproate)</li> </ul> <p><u>Relevant Research Groups</u></p> <ul style="list-style-type: none"> <li>• Brain Research UK</li> <li>• Cochrane Epilepsy Group</li> <li>• Cochrane UK</li> <li>• Epilepsy Research UK</li> <li>• Genomics England</li> <li>• MRC Clinical Trials Unit</li> <li>• National Hospital for Neurology and Neurosurgery</li> <li>• National Institute for Health Research</li> </ul> <p><u>Associated Public Health Groups</u></p> <ul style="list-style-type: none"> <li>• UK Health Security Agency</li> <li>• Public Health Wales</li> </ul>
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NICE is committed to promoting equality, eliminating unlawful discrimination and fostering good relations between people who share a protected characteristic and those who do not. Please let us know if we have missed any important organisations from the stakeholder list, and which organisations we should include that have a particular focus on relevant equality issues.

**Definitions:**

Consultees

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Organisations that accept an invitation to participate in the evaluation; the company that markets the technology; national professional organisations; national patient organisations; the Department of Health and Social Care and the Welsh Government and relevant NHS organisations in England.

The company that markets the technology is invited to make an evidence submission, respond to consultations, nominate clinical experts and has the right to appeal against the Final Draft Guidance (FDG).

All non-company consultees are invited to submit a statement<sup>1</sup>, respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Draft Guidance (FDG).

### Commentators

Organisations that engage in the evaluation process but that are not asked to prepare an evidence submission or statement, are able to respond to consultations and they receive the FDG for information only, without right of appeal. These organisations are: companies that market comparator technologies; Healthcare Improvement Scotland; related research groups where appropriate (for example, the Medical Research Council [MRC], National Cancer Research Institute); other groups (for example, the NHS Confederation, NHS Alliance, and the British National Formulary).

All non-company commentators are invited to nominate clinical or patient experts.

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<sup>1</sup> Non company consultees are invited to submit statements relevant to the group they are representing.